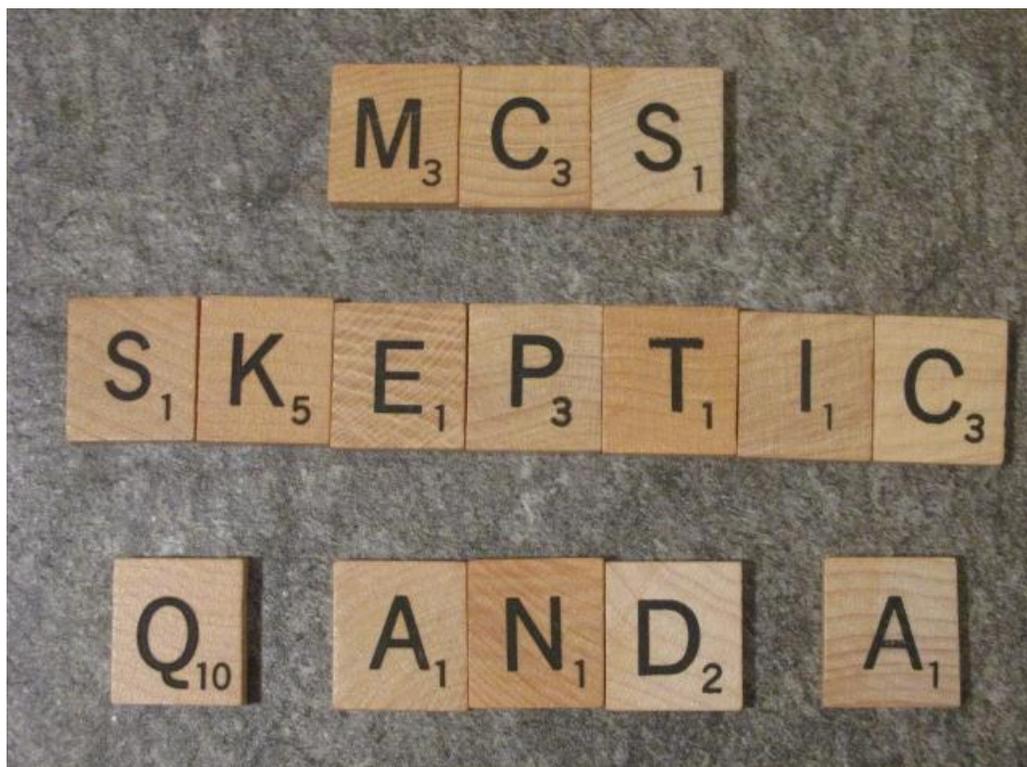


## The MCS skeptic's questions and answers



**People who are skeptical that MCS is a “real” disease often point to what they see as inconsistencies and other problems. Here we explain what the real story is with those seemingly contradictory observations.**

*Keywords: MCS, multiple chemical sensitivity, skeptic, FAQ, questions, social media*

**When I visited last week, everything was fine. This week she says my clothes smell. They are the same clothes!**

This actually happens a lot. If the clothes were washed in between, they could have been contaminated by the washing machine or clothes dryer (especially if using a shared machine). It also matters a great deal where those clothes have been. They pick up fumes like a sponge and then slowly release them again. Hardware stores, grocery stores and public restrooms are notorious for stinking up clothes, which the people who wear them cannot smell themselves.

**He says he gets sick from printed materials, but then he has a colorful calendar hanging on his wall.**

## 2 MCS skeptic Q and A

This was a comment to a video program about people with MCS. When printed materials are exposed to air, the fumes become less over time. This is called offgassing. People offgas things they do not tolerate before taking them into their homes.

In this particular case, each page of the calendar was exposed to air for a week. It took three months to make the whole calendar inert. But the journalist never asked about it.

### **They just seem nutty.**

To them living the chemical lifestyle seems nutty. Why do people want to smell of harsh chemicals and douse themselves with carcinogens every morning? And then all day breathe in dozens of chemicals that have never been tested for any health effects? Just because most people do it doesn't make it sane.

MCS can impose major lifestyle changes that often seem strange to outsiders. What is "nutty" is very much in the eye of the beholder.

### **She has a whole cabinet full of pills with nutritional supplements. That looks ridiculous.**

When the regular doctors fail to help, people turn to alternative medicine. It's a jungle with a lot of options to try and very little good guidance. It is mostly trial and error to see what may help. Maybe you have to take this herb for some months before it helps? It is really easy to gather a large collection, and it can be hard to let go of the hope some might work.

This is not particular to MCS. In the early years of the AIDS epidemic it was the same way, which is shown in the film *Dallas Buyers Club*, and the book *How to survive a plague*. Other examples are tuberculosis and cancer.

When the Chernobyl nuclear power plant blew up in 1986, doctors and officials offered no help to those exposed. Instead, people tried all sorts of remedies to try to protect themselves.

### **I took a shower and put on fresh clothes washed in baking soda, but it still wasn't good enough.**

If you live the toxic lifestyle, you can't become nontoxic overnight. Showering and fresh clothes helps, but you are still going to perspire toxic chemicals for

weeks or months after you stopped using them. Your body has stored those chemicals for years.

Some of the toxic laundry products cannot be washed out of the clothes, especially not dryer sheets (fabric softeners).

**I have MCS and I don't have all those problems these people have. They are just wimps.**

The vast majority of people with MCS have the milder versions of the illness. They are able to work and have a social life, if they just lessen their use of toxic products.

According to one Danish and one American survey, the really severe cases are only about 3 percent of the overall MCS population.

**He uses a plastic gas mask, I thought plastic "offgassed."**

A new plastic mask is indeed toxic. Some people cope by offgassing their masks for several months before actually using them.

**She says she lives in isolation, but here she is, out in public.**

The forced isolation is a big problem. Sometimes people with MCS just want to play "normal" for a day and take the consequences. It is really no different from grandma who gathers her strength to attend an important family gathering.

The Covid-19 pandemic should have made this more understandable.

**They attend support group meetings and develop friendships with other sufferers.**

With friends and family often unwilling to stop using fragrances and toxic laundry products, people with MCS frequently have to make friends with other sufferers to have a social life.

It is also helpful to talk to someone who understands what they are going through. That is similar to veterans, where only another veteran can listen with understanding of what it means to be in a war-zone. Civilians simply have no idea.

**They just want to live like hermits.**

#### 4 MCS skeptic Q and A

This ridiculous assertion came from some British psychiatrists who are often touted to be experts on MCS, despite they clearly understand very little.

The reality is that social isolation can be forced upon people with severe MCS because their family and friends refuse to tone down their use of chemicals. It is not a voluntary choice.

People with MCS refer to it as a “lonely disease.” Some move to areas where there are MCS communities, so they can have a social life.

**MCS is virtually nonexistent outside western industrialized countries, despite the globalization of chemical use.**

This is another falsehood in *The Guardian*. A 2022 article cites a 2001 article! Since then, MCS has been documented all over the world, from Japan, South Korea and Indonesia to Uruguay, Brazil and Greenland. They just didn’t look before, and made unfounded assumptions.

**They just get anxious whenever they smell something.**

Some with severe MCS can get sick even when the fumes are so faint they can’t smell anything.

A few people with MCS have completely lost their sense of smell. Yet they still get sick from “smells.”

Since nearly all things that have a “smell” can cause reactions, it makes sense to be concerned about anything that smells. Better safe than sorry.

**He can work on his own house, but he can’t work a job!**

Those two things are hugely different, even though it doesn’t look like it. People with MCS often struggle with fatigue, there may be just a “strong day” now and then, which is when such work will be done. You don’t see the down days. A boss won’t accept a worker who can only work now and then.

Also, when doing work at home, they can choose the exact materials to use, those that are the safest. And limit the exposure to just a few minutes at a time. And making sure there is plenty of ventilation too. When working in a job, it is usually not possible to control these things.

**He complains that I smell of perfume. I don't use any, he is imagining things.**

Everything you put on your body every morning is perfumed, unless you've made a real effort to seek out products that are truly fragrance free. You just don't notice the smell, since you breathe it in 24 hours a day.

Even products labeled "unscented" may not be fragrance free. They "just" have a "masking fragrance," so you still can't smell the nasty chemicals.

**They have two suicides a year in Snowflake.**

This myth was created by an article in *The Guardian*. The reality is that there have been three suicides in the Snowflake MCS community since it started in 1988. Two of them happened the year before the journalist came to visit. Other media then copied the myth.

We are not absolutely sure why the three died, but we know that two of them were housebound for years and depended on hired help. We also know that both of them had run out of savings and could no longer pay for the help they needed. Arizona does not help pay for home help. Medicare pays for some forms of assisted living, but they do not accommodate people with MCS.

Studies show that people with disabilities have higher rates of suicide, and the risk goes up the more limitations they have. Severe MCS imposes severe limitations.

**Scientists have done studies where these people could not tell the difference between fresh air and chemical fumes.**

There have been several studies where people with MCS didn't know whether they were exposed to a chemical or not. A big problem with most of these studies is that the chemical has a smell, which can give it away. To make it impossible to smell the difference, they add a fragrance to both the chemical fume and the clean air. But now the "clean air" isn't clean any longer. Any kind of fragrance can be a problem for people with MCS, including essential oils.

People undergoing chemotherapy for cancer often get symptoms from placebos they think are chemo drugs. Not any different from some people with MCS, except we don't call them malingerers.

There are many other problems with these types of "provocation tests." They are nearly impossible to do correctly.

**They are all ...**

About 70% are women. Most have allergies and asthma, and they are usually in their thirties or forties when they get MCS. Many other diseases are dominated by women such as nearly all autoimmune diseases. Men dominate Lou Gehrig's (ALS) and autism.

There have been several theories of an "MCS profile," but they were debunked by actual science. MCS can hit people in all parts of the world, all races, all levels of education and wealth, and whether they have prior mental illness or not. There are also all types of personalities, political leanings and religious beliefs.

**They don't look sick.**

People with MCS have good days and bad days. You probably won't see them on a bad day, so what you see is when they are at their best.

People with autoimmune diseases, asthma, diabetes and heart disease normally don't look sick either. Same for mastocytosis, etc.

**Scientific studies say they have anxieties, that's all it is.**

The studies show that people with MCS are more likely to have depression and anxiety, but it is not all of them. This is also the case for people with other life-altering diseases, such as severe asthma.

**It is just mass hysteria.**

Most people get MCS without having heard about it before. Before the internet, it was common that the sick people had to search for years before finding a doctor who knew what it was.

"Mass hysteria" is a derogatory term, a more polite one is "mass psychogenic illness." The myth that MCS is a "mass" disease may come from media reports of some "sick buildings" where many people got sick at the same time. It is actually rare that multiple people get MCS at the same time.

Mass psychogenic illnesses usually happens to teenagers, while MCS mostly starts when people are older.

**Why do these people not go see a psychiatrist?**

MCS is not a psychiatric disease, but many have actually tried various psychiatric treatments. They may try that early on, as their regular doctor and family members talk them into trying it.

There are multiple surveys and studies of whether psychiatry helped, and mostly it didn't help at all. Many even reported that the medications were harmful to them – drugs are chemicals too.

The reports where psychiatry did help are usually just on one single patient, and with no follow-up to see if the treatment lasted.

Some try psychologic treatments to help with the trauma of living with MCS. That is no different from coping with the trauma of other life-altering diseases or from a bad car accident.

### **She lives in a car, and that is not toxic?**

Cars are not wonderful, but are sometimes the least-terrible option for someone who cannot find or afford a healthy house. The cars are usually many years old, so a lot of the toxics are aired out. Some people remove the interior plastic panels, etc. There have been a few car models that were less toxic, such as from Lexus and Volvo.

### **Doctors don't even believe it is real!**

Some do, some don't. Many are not sure. The medical community is divided. One reason is a turf war, another is that MCS contradicts current dogma. There is a lot we still don't know about MCS. In the past doctors also said many other illnesses were "all in their head," such as ulcers, asthma, migraines, celiac, lead poisoning, endometriosis, Lyme and temporomandibular jaw (TMJ). Many still believe that about Long Covid, fibromyalgia and chronic fatigue.

In the 1980s and 1990s there were lively disagreements among scientists whether second-hand smoking was harmful or not. It was vital to the tobacco industry to keep that topic controversial, just as it is for some to keep MCS controversial.

### **Afterword**

The comments listed here are reasonable observations considering what little information people had. Life with MCS is difficult to understand for outsiders, and there is very little accurate information available. Some doctors have strong

## 8 MCS skeptic Q and A

opinions about MCS, even though they have very little actual experience with MCS patients.

Popular media is a common source of disinformation. That is made by a journalist who knows hardly anything about MCS and doesn't have the time to learn about it, but still has lots of opinions.

Popular media makes things “interesting” by focusing on controversies and anything that seems unusual. They need to keep people's attention so they can display more advertising. Otherwise they go bankrupt.

It is just 3% of the overall MCS population that are the really severe cases. They are the ones who have to make major lifestyle changes. How often does the media talk about the other 97%? Just about never.

Then clever editing does the rest. Popular media is for entertainment, not educating people about anything.

Another common mistake is assuming anyone with MCS is an expert. There is a lot of opinions presented as fact on MCS social media, just as there is on so many other social media. People with MCS are no better or worse than other people.

Journalists and other people make judgements based on their own life experiences and what they hear from their peers. If you do not have MCS it is really hard to understand what it means to have it. That is not unusual. A young and healthy person has no way to really understand what old age is like. A healthy person cannot grasp what it means to be disabled.

A lot of us think we understand these things, until we actually land in that situation.

### **About this article**

We found most of these skeptical voices on social media. Two are from medical journals. Some are edited versions of the real postings. To keep it simple we provided short answers without referencing more detailed information.

### **More information**

For more information about MCS, what life with this illness is like, about the controversies and references to scientific journals, please go to [www.eiwellspring.org/intromenu.html](http://www.eiwellspring.org/intromenu.html)

